



# ACCESS HEARING AND VISION SERVICES



*Prepared By*





## **Methodology:**

Beginning in July of 2015, changes to the system of care for children with hearing and vision impairments enrolled in Family Centered Early Supports and Services (FCESS) required the integration of vision and hearing therapies and services directly into FCESS programs. Simultaneously, efforts were being made to build the capacity of the system and individual programs. This was an adjustment in the delivery of services for all involved.

As with any major modification to service delivery there were concerns that the services be re-organized to benefit families and provide appropriate services for children. Efforts included gathering input through stakeholder groups which included:

- ♦ State office staff,
- ♦ Hearing & vision organizations, professionals,
- ♦ FCESS Agencies and professionals who work within the agency, and
- ♦ Families

In addition, individual meetings were held with NH Deaf and Hard of Hearing Services, Future in Sight (formerly NH Association for the Blind), and the Deaf and Hard of Hearing Commission. Other input was gathered through one to one meetings, phone calls and e-mails from families, advocates, and professionals in the field. As a result of stakeholder concerns expressed during these interactions, twenty six questions were developed to be asked of families via a telephone interview.

Of the 84 families enrolled for vision and/or hearing services 48 participated in phone interviews. The interviews were conducted with families by an objective, 3rd party consultant and entered into a survey monkey format for analysis by staff at NHFV.

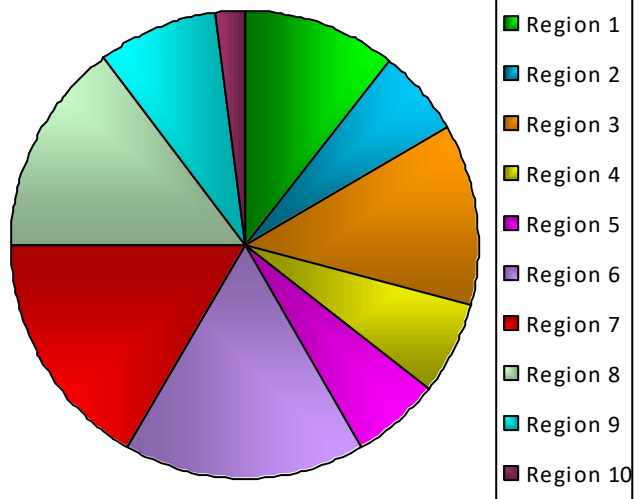
♥ To protect the identity of the families, personally identifiable information has been removed.

▪ This report was developed through funding from the U.S. Department of Education, Office of Special Education Programs' (OSEP's) Part C of the IDEA, under grant #H181A160127.



**Question # 1** What Region are you from?

	Response Percent	Response Count
Region 1	10.4%	5
Region 2	6.3%	3
Region 3	12.5%	6
Region 4	6.3%	3
Region 5	6.3%	3
Region 6	16.7%	8
Region 7	16.7%	8
Region 8	14.6%	7
Region 9	8.3%	4
Region 10	2.1%	1
<b>Answered question</b>		<b>48</b>



**Question #2** What program are you enrolled in?

	Response Percent	Response Count
Northern Human Services	10.4%	5
Children's Unlimited	0.0%	0
PathWays of the River Valley	8.3%	4
Lakes Region Community Services	10.4%	5
Community Bridges	6.3%	3
Monadnock Developmental Services	2.1%	1
Rise...for baby and family	4.2%	2
Gateways Community Services	8.3%	4
The Children's Pyramid R6	8.3%	4
The Moore Center	6.3%	3
Easter Seals R7	10.4%	5
Child and Family Services	4.2%	2
Richie McFarland Children's Center	10.4%	5
Community Partners	8.3%	4
Easter Seals R10	0.0%	0
The Children's Pyramid R10	2.1%	1
Unsure	0.0%	0
<b>Answered question</b>		<b>48</b>

### Question # 3 What are your child's needs?

	Response Percent	Response Count
Vision	18.8%	9
Hearing	27.1%	13
Vision and Hearing	0.0%	0
Other (please specify)	54.2%	26
<b>Answered question</b>		<b>48</b>

Descriptions provided from families to clarify the “other” diagnosis very often included vision and or hearing but they felt it important to clarify that those were not the primary areas of concern for their family, instead listing a number of additional or co-occurring diagnoses. Some families also listed “other” so they could specify the exact vision/hearing difficulty.

Among the specific diagnosis listed were Down’s syndrome, microcephaly, seizures, physical delays, multiple issues, global delays, g-tube, chromosome disorders, genetic Conditions, type 1 diabetes, hydrocephaly, speech delays and multiple medical diagnoses.

### Question # 4 Who is your hearing/vision provider?

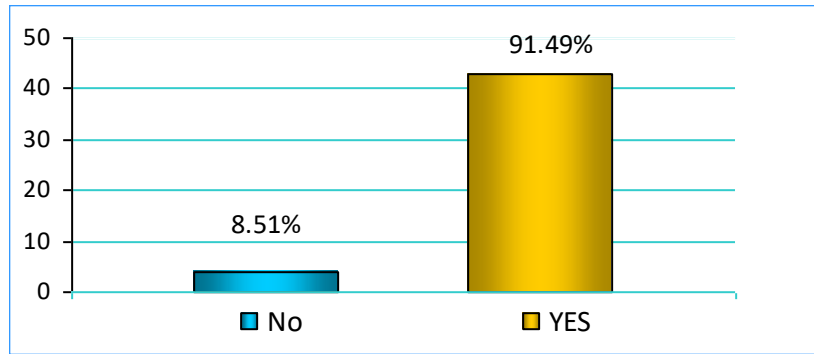
Very few of the families could identify their service provider’s full name. The majority of families could only identify their provider by first name or agency association. Some families were able to provide the names of multiple individuals if they had experienced vision/hearing provider changes. One family could identify first name only and was not sure of the agency, while another family didn’t know the person’s name or affiliation, however they did acknowledge that she was in the home monthly. There was confusion for one family who answered with the name of their audiologist and even when prompted did not identify their in-home provider as a hearing/vision provider.

### Question # 5 What type of specialist is your hearing /vision provider?

Of the 34 who responded “other” 19 identified an occupational therapist (OT) and 6 identified a speech therapist. The following were each listed once: speech assistant, OT, audiologist, BS Early Childhood Education, Masters in Physical Therapy, speech/teacher of visually impaired, teacher of the deaf, Speech therapist, and audio visual therapist, NH Association for the Blind and Dartmouth Hitchcock. One family said other but didn’t identify the specialty.

	Response Percent	Response Count
Teacher of the Deaf (TOD)	12.5%	6
Audio Verbal Therapist	0.0%	0
Teacher of the Visually Impaired	14.6%	7
Unsure	4.2%	2
Other (please specify)	70.8%	34

**Question # 6** Did your FCESS Service Coordinator help you understand your options?



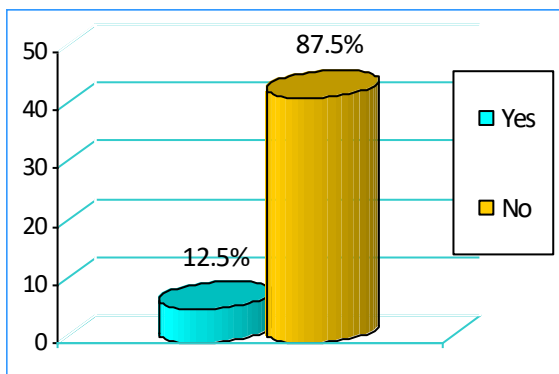
Twelve families gave additional explanations when answering question #6 which included comments such as “yes and no”, “just a little bit” “overwhelming”, “child was in foster care – there was no choice”, “they said they would start 1 time per week”, “good relationship with the agency from past experience”, “someone spoke briefly about Special Medical Services and Nutrition Feeding and Swallowing”, “hard to remember”. One family indicated they were given the option between two different FCESS programs.

**Question # 7** Were you informed of the types of specialists available?

	Response Percent	Response Count
Yes	76.1%	35
No	23.9%	11
Comment Details		8
<b>Answered question</b>		<b>46</b>
<b>Skipped question</b>		<b>2</b>

Within the comments only one family identified the options available and the option they specified was OT or PT. Three said it was “hard to remember”, and one person indicated the service was set up through foster care. Three people identified who they started with, but did not identify if they were provided with information about the types of specialists.

**Question # 8** Were you given a choice of who your specialist or consultant would be?



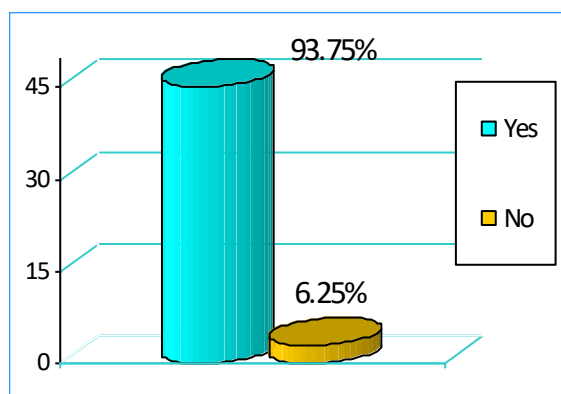
Forty-eight families provided the following comments regarding choice of specialist or consultant:

- Services were added as needed.
- We switched agencies because of unprofessionalism.
- At the evaluation they decided who would be best.
- We had a variety of providers. Started with one then another came.
- Having a hard time getting speech therapist.
- Wanted speech therapist but was given physical therapist.
- Wanted physical therapist but could only get occupational therapist through FCESS.
- Needed a specialist but family had to find their own and then FCESS would contract with provider.
- Given physical therapist and someone else who did an evaluation.

**Continued Responses from Question # 8** *Were you given a choice of who your specialist or consultant would be?*

- Someone was assigned but if mother didn't like them the program would try to find someone else.
- Specifically requested a particular provider.
- It would be nice to have one head person come and talk about the program before a person showed up and started.
- Services provided by FCESS are considered transdisciplinary but we have had to request speech be added because of outside professional recommendations and it was.

**Question # 9** *Were you included in the planning of your hearing/vision consultation and/or services?*

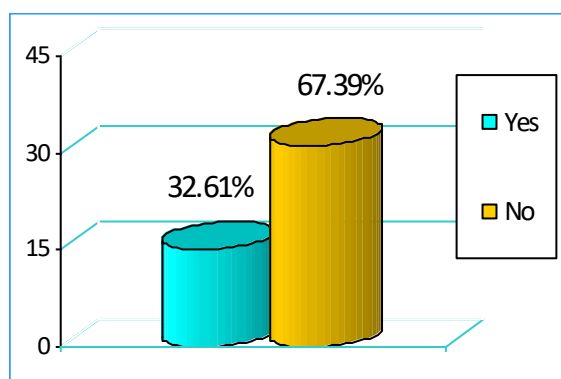


Forty-five families indicated they were a part of planning, included in planned services, setting goals, talking about child's need together and were asked what they were "seeing the child do". Others felt they needed the ideas and experience of the professionals but were also always asked what they expected for the child. One family indicated they were asked what was the family preference and what was needed by the child? Some families indicated that they asked questions and were given answers while one family felt they were told what was needed. Another family indicated they were included in "some stuff" but didn't feel like they really had a voice.

**Question # 10** *How long did you wait for a consult?*

The majority of the 48 families indicated they didn't wait long. Most said 2-3 weeks and/or within the month. Three families felt they waited "quite a while" when services were being integrated into FCESS. Five families said they waited 2 months, with one person indicating she called the state for assistance. One person said they didn't wait long but changes happen often.

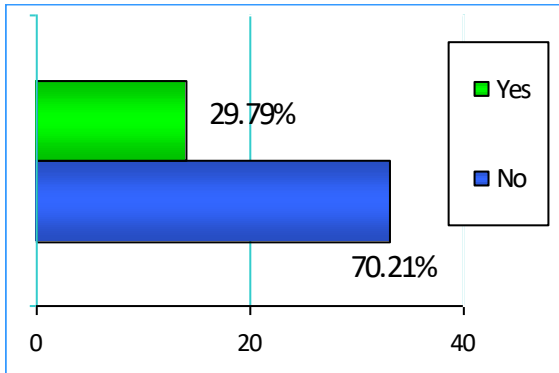
**Question # 11** *Were there any delays in your hearing/vision services?*



Families attributed delays in vision/hearing services to the change in the system as the integration occurred, paperwork, scheduling and children's medical testing. Some families also indicated they couldn't remember if there were any delays.

- Not long, within a month.
- Unsure - didn't get hearing aides until 13 months and not from audiologist at DHMC had to go to someplace else.
- Waited about 2 weeks.
- Had MICE 2 months then service shifted before service began again.

**Question # 12** Did your hearing/vision provider have to cancel any visits?



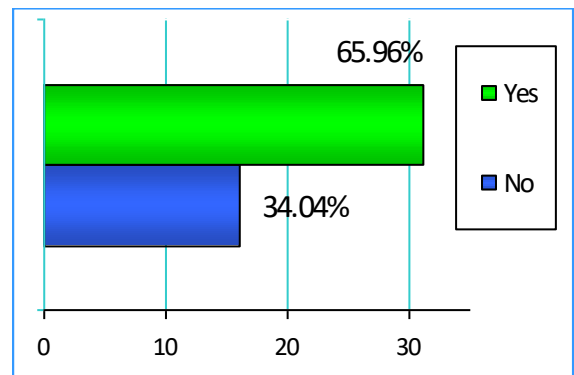
Reasons for cancellations included illness, weather, car trouble, ability to meet schedule needs, and staffing.

- Snowstorm
- Can't remember but don't think so.

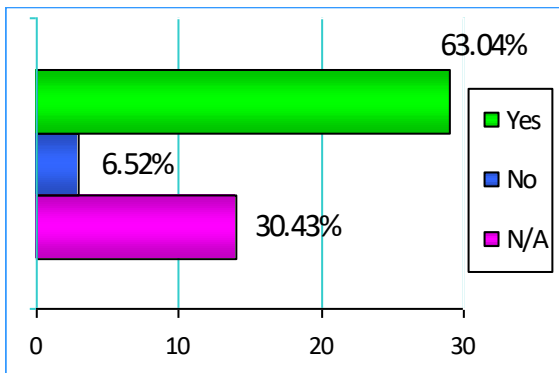
**Question # 13** Did you have to cancel any hearing/vision sessions?

Reasons for cancellation included illness, other appointments, weather, and schedule conflicts.

- When either mother or child was sick
- Hospitalizations, and sickness
- Schedule conflicts
- Medical appointments, sick child



**Question # 14** If applicable, were any cancellations rescheduled?



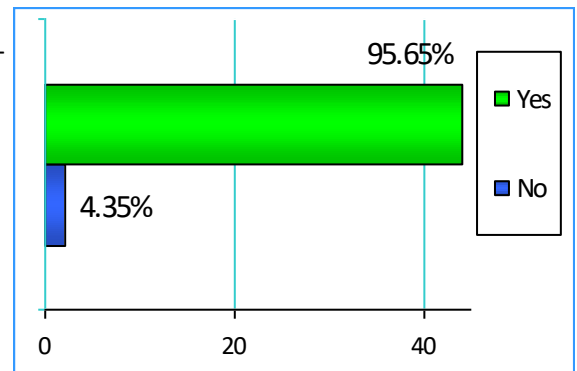
Families indicated that rescheduling happened if available, or they came the next week if possible. Re-scheduling was hard. Others said it was difficult to remember with so many appointments and it was some time ago.

- So many sicknesses and appointments hard to remember but only one person to be available to give services and they have many clients to see.
- Came on the regular schedule the next week

**Question # 15** Did your FCESS provider and hearing/vision consultant work as a team?

The majority of the families said FCESS and the hearing/vision consultant scheduled some visits together, some said staff sent notes to one another. One family did indicate that when FCESS and the hearing/vision consultant came together she did not feel included.

- Services 2-3 times a month. One time for FC-ESS Coordinator and 1X for Hearing and then 1X for both together.



**Question # 16** Where were your hearing/vision services provided?

	Response Percent	Response Count
Home	95.8%	46
Child Care	2.1%	1
Other (please specify)	10.4%	5
Answered question		48

Two families indicated they received services at the ESS center, two at a medical providers office and one said “occasionally at childcare”.

**Question # 17** Do you feel you are prepared to use the hearing/vision strategies when no professionals are around?

	Response Percent	Response Count
Yes	97.9%	47
No	2.1%	1
Answered question		48

Comments included: Very helpful, definitely, brought ideas for me to follow through, one staff member worked with the child while one explained to the family what was needed for improvement, learned one or two signs at each session, no strategies given - they just played with the child and family is still unclear as to what the child is capable of seeing.

**Question # 18** Tell us about your first visit with the hearing/vision consultant.

- Twenty-one families indicated they couldn’t remember the first visit, although some did remember where it occurred.
- One family remembered it as an “introduction” to new staff visit.
- Five families remembered the visit as an assessment visit.
- Two families remembered it as observation time with questions for the family and some responses to family questions.
- One families felt it was an opportunity for them to tell the consultant how to follow through on recommendations made by previous professionals.
- Five families did not give responses addressing the question.
- Three families felt the first visit was confusing with multiple people present.
- Three families felt it was a visit for paperwork, introduction of goals and plans and services. One of the four indicated services were explained and she was asked if she wanted them.
- Three families felt the visit was very helpful. Phrases such as “very kind”, “knowledgeable”, and “patient” were used by these families.
- One family felt the specialist was not up to date on vision needs of the child.
- One family indicated the visit was “very brief, not much happened and they were provided no ideas until the second visit”.
- One family felt the visit entailed getting the child to look at toys or items to see how he processed.
- One family remembered the specialist speaking to the area of vision of the child and what tools would be helpful.



**Question # 19** Tell us about your overall experience with vision/hearing services.

Descriptive responses to this question included a wide array of adjectives including okay, wonderful, satisfactory, good, great, very helpful, positive and professional.

Additional feedback from families included:

- Consultant provides information, resources when needed.
- This is an extremely valuable tool outside what EI team can provide you especially if provider has a hearing impairment themselves, they can give a perspective of the world as they see it (hear it) and how to work within the system.
- Consultant was immediately able to assess needs and make suggestions of appointments and resources that have been helpful.
- Vision specialist is amazing meets child's needs and understands when child is not well and revises plans.
- TOD helped family with any questions, Family would text TOD questions and TOD would video self and send it through internet so family could use strategies with child.



Concerns about the program included:

- Consultant mostly observed and critiqued.
- Loved it but understood it was time limited, would like TOD on regular weekly schedule year round.
- Desire to receive services more than one time per month and
- One family was still waiting for a teacher of deaf to be available.

One person gave an answer that did not address the question and one skipped the question.

**Question # 20** Tell us about your overall experience with FCESS

Responses from families fell into three categories. Those who were very pleased, responding with a description of their experiences as wonderful, great, awesome, love it, excellent, and very supportive. Families felt FCESS was helpful to them in understanding milestones in development, and providing resources. Two families were particularly pleased that FCESS helped them to get services from another state when they couldn't be accessed in NH. One family was particularly pleased that the TOD helps FCESS staff and assistant understand strategies to use at their visits.

The second category included a number of families who felt their experience with FCESS was "Okay" and discussed the difficulty of getting services set up, staff cancellations of appointments, staff with their own agenda, confusion over determining who does what and an inability to get the specific services they felt were needed. Multiple families mentioned an inability to get the quantity of services they felt their child needed.

The third category and smallest subset of families rated their experiences as "good" with explanations such as "speech therapy is really good, everyone is nice however not sure that they are up to date on what a child who is deaf needs". There were also specific things families identified as needing greater focus – such as learning to walk.

### **Question # 21** What did you learn?



Family response to this question included statements such as:

- children needed vision services,
- child not hearing correctly,
- child can do more than function and do more than expected,
- strategies,
- information for use when child turns 3,
- skills, techniques, exercises and materials for working with child.

Others were unable to specify what they learned but felt they “learned a lot”.

A family felt they received a crash course in the “culture piece” - How to interact with a non-hearing person and how to work with others who can’t hear.

Families felt they were empowered to advocate for their child and this helped the parent to support the child in advocating for her own needs. They learned how to how to navigate the system and about resources while also receiving comfort. Some families indicated questions they had were answered and one family felt the service reinforced things she already knew.

One family felt that prior to service change was provided they received wonderful information. Mother doesn't know of anyone in the area who knows exactly the same information. One family mentioned that new staff brought a light box.

There were families who felt they didn’t learn much or nothing specific, or were unsure of what they learned.

### **Question # 22** What do you hope your child will gain from participating in FCESS hearing/vision services?

- ♦ Eight families responded that they would like their children to live “normal” lives like any other child.
- ♦ Eight families addressed their desire for their child to gain independence, success, confidence and maximizing their potential as positive members of society.
- ♦ Families were seeking integration into regular preschool, expecting that FCESS would be a positive support in their transition to school.
- ♦ Learning to walk and talk, continue to develop as much as can be expected, and continuing to meet milestones were priorities for many of the families interviewed. Children learning to advocate for their own needs, feeling a decrease in frustration and being prepared for preschool with the ability to communicate were priorities.
- ♦ Dealing with complicated medical issues made it difficult for some families to set expectations of their participation in FCESS hearing/vision services. Families expressed hope that FCESS Vision and Hearing would help the child learn to communicate with support and help parents learn more about what their child is capable of doing. They wished to gain a better understanding of vision and hearing loss and its effect on their children.

### **Question # 23** Are there any other comments you'd like to share?

Seven families had no additional comments.

- ♦ The majority of families indicated they were very pleased and loved the program.
- ♦ Home services are especially appreciated as families already had a large number of appointments requiring them to be out of the home.
- ♦ They appreciated access to FCESS staff through text and/or phone calls.
- ♦ Many mentioned the staff's willingness to "go above and beyond" for their families.
- ♦ Some comments were specific to the delivery of both FCESS and Hearing and Vision services together - providing additional perspectives that positively affected their children. Level of knowledge provided by the Vision and Hearing consultants was singled out as being appreciated.
- ♦ Families felt the expertise of two providers had a stronger impact on their children than having one provider would have had.
- ♦ One family indicated she received carbon copies of notes from the Hearing and Vision Consultant; however she would like to be able to receive this type of information digitally.
- ♦ One family felt that multiple care coordinators coming into the house "all doing the same things" was redundant and the money could have been better spend on direct services.

Several families indicated the need for additional funding to FCESS to support additional services. They felt they were not able to access the therapies their children needed. It was mentioned that additional funding would also allow FCESS to hire more qualified providers. An on-going concern was the inability to get services from a Teacher of the Deaf outside of the "school year". Difficulty of scheduling with multiple providers was also a concern.

### **Summary**

This report was compiled by an objective third party who was not involved in either the actual design of the survey or the interviews done with families. The notes from the interviewer and the results previously entered into Survey Monkey were made available to the author.

FCESS and Hearing and Vision services are definitely appreciated and valued by the families who receive them. The majority of families describe the services and staff who deliver the services in positive, if not glowing, terms. It is clear that families are immensely grateful for the work that this system and the professionals who work within it do on behalf of children and families. The results of the survey indicate that the integration of services - once they begin - continues to provide families with information, resources and support for their child with a diagnosed vision/hearing need. Families who had children with medical concerns and vision/hearing needs were very clear to the interviewer that the medical needs were the families' priorities.



## **Summary** ... continued

In question #10 there was a range of wait times identified from 2 weeks to as much as two months for a consultation. Immediately following in question # 11, families indicated that they did not wait for services. Because these questions followed one another the author is unable to determine if families were clear about the difference between the initial consult visit and the start of on-going service visits. The author would also like more information on the process of having a consultant assigned to a family. For instance, are the consults only scheduled when the consultant has the time in their schedules to provide on going services? Also concerning to the author was a response to Question 19 where a family indicated they were “still waiting” for a ‘teacher of the deaf’ (TOD). As the author was not the interviewer there is no way to tell how long the wait has been. These questions make it difficult to determine if families are receiving services within an appropriate timeframe.



An on-going concern raised by families during the survey was the schedule that the majority of TOD's work. They are available only during the schoolyear making it impossible to receive services through the summer months. Because children between the ages of 0-3 are developing and meeting milestones at a rapid pace having a break in services over the summer is concerning. The author believes this is a problem the Part C office is aware of and hopes that it will be a priority for future system development.

In question # 8, “Were you given a choice of who your specialist or consultant would be?” 87.5% percent of families felt they had no choice regarding who would be providing services to their son or daughter. When combined with the anecdotal answers provided to question #9 “Were you included in the planning of your hearing/vision consultation and/or services” there appears to be an opportunity for education and significant improvement. While families said yes they were involved, further reading of the comments included; “I was there”, “I was told what was needed”, “I felt that I had no voice”, contradicts statements that families were involved. The author strongly recommends that the Part C Office work in partnership with FCESS programs, parent organizations and families to strengthen the family voice within FCESS.

If future surveys are planned to provide information to the Part C office the author would recommend that a consultant be involved from beginning to end of the process. There was considerable difficulty in extrapolating meaning from open ended questions when the interviewer was not the author of the report. The design of the survey also did not lend itself well to statistical analysis as the majority of the questions were open-ended. While this information is often felt to be “richer” information, it makes it difficult to recommend changes in practice based on data collected.